

**Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design**

MORRISON, Cecily and DEARDEN, Andy <<http://orcid.org/0000-0002-5706-5978>>

Available from Sheffield Hallam University Research Archive (SHURA) at:  
<http://shura.shu.ac.uk/7151/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

**Published version**

MORRISON, Cecily and DEARDEN, Andy (2013). Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design. *Health Policy*, 112 (3), 179-186.

---

**Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>



# Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design<sup>☆</sup>



Cecily Morrison<sup>a,\*</sup>, Andy Dearden<sup>b,1</sup>

<sup>a</sup> Engineering Design Centre, University of Cambridge, Engineering Department, Trumpington Street, Cambridge, CB2 1PZ, UK

<sup>b</sup> User-Centred Healthcare Design, Sheffield Hallam University, Cantor Building, 153 Arundel Street, Sheffield, S1 2RU, UK

## ARTICLE INFO

### Article history:

Received 22 November 2012

Received in revised form 8 May 2013

Accepted 17 May 2013

### Keywords:

Public participation (PPI)  
Participatory design  
Representational artefacts  
Older people  
Health services

## ABSTRACT

A number of recent policies promote public participation in health service design. Yet, a growing literature has articulated a gap between policy aims and actual practice resulting in public participation becoming tokenistic. Drawing on theory from participatory design, we argue that choosing appropriate artefacts to act as representations can structure discussions between public participants and health professionals in ways that both groups find meaningful and valid. Through a case study of a service improvement project in outpatient services for older people, we describe three representational artefacts: emotion maps, stories, and tracing paper, and explain how they helped to mediate interactions between public participants and health professionals. We suggest that using such representational artefacts can provide an alternative approach to participation that stands in contrast to the current focus on the professionalisation of public participants. We conclude that including participatory designers in projects, to choose or design appropriate representational artefacts, can help to address the policy–practice gap of including public participants in health service design.

© 2013 The Authors. Published by Elsevier Ireland Ltd. All rights reserved.

## 1. Introduction

There is a strong policy drive to involve patients and the public in the design of health services for both pragmatic and ethical reasons [1]. In the UK, for example, the Department of Health's report, *Creating a Patient-Led NHS* [2], highlights the contribution of public participation in creating responsive, patient-centred services, while the *National Health Service Act 2006* [3] requires that services are made

accountable to the public through consultation, providing the public with a mechanism to influence decision-making. Policies to encourage participation in health service design can be seen across a wide range of high income countries [4].

Despite efforts to engender participation, there is a growing literature that suggests there is a gap between these policy aims and actual practice [5]. Current participation activities provide little opportunity for impact [6], and when they do, other barriers arise. Public participants can find it difficult to add their experiential knowledge to the conversation and have their contributions considered legitimate within a discourse that is often focused on specialised scientific knowledge [7,8]. The result is that although public participation is now embedded in the structures that support healthcare, its role is frequently tokenistic and the public are often unable to affect outcomes.

<sup>☆</sup> This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike License, which permits non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

\* Corresponding author. Tel.: +44 1223 748245; fax: +44 1223 332662.

E-mail addresses: [cpm38@cam.ac.uk](mailto:cpm38@cam.ac.uk) (C. Morrison),

[A.M.Dearden@shu.ac.uk](mailto:A.M.Dearden@shu.ac.uk) (A. Dearden).

<sup>1</sup> Tel.: +44 114 225 6878; fax: +44 114 225 3161.

Enabling meaningful, as opposed to tokenistic, participation then requires finding a way for public participants to express themselves and their contributions that is both understandable and deemed valid by health professionals when designing health services. We draw upon theoretical constructs and practical tools from the field of participatory design to do this. In particular, we focus on the use of representational artefacts to structure discussions by providing depictions of current situations or future design proposals in an appropriate language for all. In this paper, we use a case study to show how representational artefacts can help to move beyond tokenistic participation in health service design, and illustrate how the approach could be used to close an important policy–practice gap.

## 2. Background

Public participation is a term that has been applied to a breadth of activities and philosophical stances, leading to much debate about its nature and purpose [9–11] and numerous attempts to characterise its diversity [12,13]. Despite differences in theoretical or philosophical approach, on the practical level, public participation remains tokenistic [12]. Healthcare institutions go through the motions of public participation, but the scope for public participants to affect change is often minimal [6,14,15]. As the opposite of tokenistic, we define meaningful participation as the ability to impact decision-making in health service design settings. Below we consider the practical challenges that must be addressed to enable meaningful participation.

### 2.1. Meaningful participation

The level of public involvement has been commonly characterised by a ladder of participation, each rung signifying the amount of weight given to the public voice [16]. Further theory development broadens this characterisation to encapsulate the mutual exchange of knowledge rather than that of a finite amount of power, and draws attention to the methods used to support participation [17]. The literature suggests that consultation is still the dominant way that the public voice is heard, a method both low on the ladders of participation and one that does not encourage a relationship of mutual knowledge exchange. Meaningful participation then must support the establishment of relationships through involving, collaborating with, or empowering public participants in such a way that they can contribute their knowledge.

One systematic review found 300 case studies that did provide opportunity for meaningful participation; however, many barriers to impacting services were discussed [15]. Public participants are often asked to partake in activities with highly structured, often opaque, protocols for communication, such as sitting on executive boards [18]. Consequently, they need to carefully direct their communication, such as target the chief executive, or as one paper describes it, ‘work the system,’ to get their voice heard, [19]. Yet, many public governors still feel that they do not have the skills to challenge professionals on the board [20]. Public participants cannot take advantage of participation

opportunities if they do not have the skills to interact in the settings in which they are placed.

Lack of receptiveness to the contribution of public participants is another barrier that has been identified. Some studies described situations in which public participation was used to legitimate decisions that organisations would have made anyway [15]. Others highlight ingrained power differences in medical culture between evidence-based medicine and personal (and thus anecdotal) experience [6]. Although anecdotes were appreciated, when resources were allocated, arguments framed in terms of evidence-based medicine had more sway. As a result, the contribution of public participants was often deemed invalid by the health professionals with whom they were interacting.

The published accounts of public participation indicate that the ability of the public to participate can be compromised by the very contexts which are meant to empower, such as being a decision-maker on a board. Accounts also suggest that when a contribution is made by public participants, it is not always deemed credible due to the relative value placed by health professionals on scientific knowledge as opposed to personal experiential knowledge. We would propose that achieving meaningful participation then requires not only providing opportunity to participate, but also facilitating participants’ ability to do so by addressing the mismatch of knowledge bases.

Thompson et al. [21] report that the ability to participate is often achieved through professionalisation of public participants. They describe how experienced public participants put significant energy into learning about the relevant science, either surrounding their condition or the research methods, in order to enhance their communication with health professionals. Participants also highlight previous qualifications (e.g. a medical degree), or recently acquired ones (e.g. training courses), to legitimate the knowledge that they do have. These tendencies are being supported through a greater emphasis on training and support for public participants in order to close what is perceived as a knowledge gap [22].

While the professionalisation of public participants may provide the ability to participate, it raises numerous issues [12]. First, it restricts public participation to those who are willing and able to gain these particular new skills. Second, the nature of the experiential knowledge that public participation is thought to offer becomes questionable, particularly if the diversity of participants is limited. Third, scientific knowledge is maintained as the dominant paradigm against which the experiential knowledge of public participants must be normalised [21]. We would suggest therefore that this approach does not enable meaningful participation.

We propose that meaningful participation requires attention to the specific methods of engagement so that they do not demand that public participants express themselves in unfamiliar ways in order to be understood or considered valid by health professionals. In the next section, we discuss how the field of participatory design has addressed these issues both theoretically and practically with representational artefacts.

## 2.2. Representational artefacts

Participatory design is a field that considers how to enable people with different knowledge bases to collaboratively design new products and services. It has a historical focus on computer systems, tracing roots to the late 70s and early 80s when there was deep dissatisfaction with computer systems that were poorly matched to the context of use, and widespread fears that automation would result in loss of jobs and deskilling of employees. Researchers worked to devise new approaches to computer systems' design that paid greater attention to the detailed practices of use, and sought to engage end-users as more active participants in the design process to shape their own future [23].

A common theme in participatory design is the need to support shared understanding of the existing situation and of future design proposals. This can be done by creating an appropriate representational artefact, an object that is being used to represent the topic of discussion. Everyday examples include maps, diagrams, pictures and props used in rehearsing a stage play. Well designed representational artefacts can both embody the questions of specialists but also be understood and manipulated by public participants. Regardless of form, appropriate use of representational artefacts reflects the emphasis in participatory design on attending not only to the allocation of authority, but also to the mechanisms and medium for discussing design proposals.

The collaborative facilitation that representational artefacts can foster is captured most clearly in the concept of boundary objects [30]. A concept originating in the field of Science and Technology Studies, Star and Griesemer [31] describe boundary objects as:

... objects that are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites (ibid, p393).

Boundary objects are a means for translating understandings and meanings between different domains, different locations, and between different temporal points within a project. Boundary objects help groups with different expertise and backgrounds to establish shared understanding. As concrete objects, they can be named, pointed to, and used by participants in identifying and repairing breakdowns in communication [32].

Many of the theoretical insights in participatory design, not surprisingly, identify language as key to mediating interactions and achieving meaningful participation. Ehn and Kyng [25] highlight that interactions in a design setting can be described as a 'language game' in the sense of Wittgenstein [26]. Language games have implicit rules that govern how and when people can speak and what they can say. For example, people have implicit knowledge on appropriate ways to chat over coffee, but may be less comfortable with the rules associated with communication in a court room or that of a design team. Ehn and Kyng suggest that active effort is needed to ensure design activities embody language games that have sufficient resemblance to ones participants have played in

the past, so that they can learn quickly how to join in the dialogue.

Representational artefacts provide one mechanism to establish language games through thoughtful construction and use. As abstract notations for describing systems, representational artefacts draw attention to some aspects of a situation or design proposal, and elide others. Bråten [27] highlights how particular representations of problems can entrench and hide power differentials in social decision settings. Using flow charts to model work processes, for example, may draw attention to questions of efficiency of workflow, but do not support discussion of the quality of working life. Consequently, using such technical representations on their own influences the language game created. This can narrow the scope of the discussion, privileging managerial priorities over those of workers.

Ehn [28] explores how the pragmatics of participation in design are influenced not only by the social norms and practices of verbal language games, but also by the form of the representations used. One key concern is the familiarity of the representations to the public participants. Unfamiliar ones cause the representation to become the conscious focus, 'present-at-hand' (*vorhanden*), rather than a tool to support the conversation, or 'ready-at-hand,' (*zuhanden*). Another concern is their physical form and properties which influences who is able to participate and how [29]. For example, information written on a whiteboard is a representation that may be more amenable to group participation than the same information projected onto a screen.

Participatory technology designers have already started to consider how to adapt these theories to the health domain. Examples include working with people with aphasia [33], people with amnesia [34], and children with autism [35]. In the case study presented below, participatory design theory is applied to outpatient services for older people. We consider how representational artefacts are used to establish the language of interaction and enable meaningful participation.

## 3. Case study

Better Outpatient Services for Older People (BOSOP) was a one year service improvement project to identify areas in a particular hospital setting that could be improved, and to explore possible solutions [36]. During this project, a design team used participatory design methods to enable older patients and staff representatives to work together to drive improvements. The approach used provided ways to give voice to the patients' perspectives about attending the outpatients' clinic, and facilitating them to take part in designing solutions. In this case study we briefly describe the design activities carried out and then reflect upon how the chosen representational artefacts enabled meaningful participation.

We draw upon a range of data collected during the project, including audio recordings of design events, video snippets, proposal and debrief documents, follow-up interviews with all participants, and interviews with the design team. As a service improvement project applying the methodology of experience based design (EBD) [37] the BOSOP project was not considered a form of research but

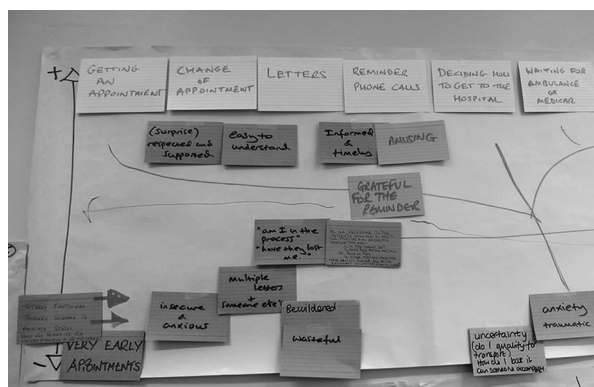


Fig. 1. Emotional map.

a service improvement initiative. Consequently, it did not require review by a medical research ethics committee in the UK. Governance for the study of the EBD methodology was covered by the Sheffield Hallam University Faculty of Arts, Computing Engineering & Sciences research ethics committee.

### 3.1. Design activities

BOSOP began by gathering people's stories. Members of a local charity visited older people in their homes and recorded their experience of their last visit to hospital and any other stories they wanted to share. These were transcribed and shared with the design team to provide a starting point for creating emotional maps, which are visual representations that highlight aspects of patient experience. In this case, the emotion maps showed the sequence of touch points through time horizontally, and illustrated the positive and negative emotions of the patient's experience of a visit to outpatients, or of a 'day in the life' of a health professional against a vertical axis, as seen in Fig. 1.

Two groups, one of patients and carers (public participants) and one of health professionals, worked separately during a half-day session to create their own maps. The public participants' session began with people retelling their stories, which prompted further stories and discussion. Participants and facilitators then wrote incidents and emotional keywords drawn from the patients' stories, onto 'post-it' notes which were placed on the map below the touchpoint they were associated with. The post-it notes were positioned vertically with strong positive emotions at the top, and strong negative emotions towards the bottom. For example, one post-it note which said, "slept in chair and clothes waiting for morning ambulance," was placed under the touchpoint, getting to hospital, with an arrow to the word anxiety. The health professionals' session was similar, but focused on 'a day in the life.'

The emotional maps provided a temporal collation of the patients' and health professionals' experiences and concerns that could be shared with the alternate group. In the session in which public participants and health professionals first came together, representatives from each group used the map to explain their perspectives, tell stories and summarise their concerns for discussion.



Fig. 2. People working around "A Road" map.

Following the sharing, the public participants and health professionals jointly prioritised issues for future design sessions. Two teams, each involving both public participants and health professionals, then worked together to design solutions. One group focused on issues of 'getting to' the hospital, and the other dealt with 'arriving at' the hospital.

A range of further participatory design activities took place in the following months to address the issues raised. In this paper, we will discuss only one of these, referred to as the 'A Road' project. It brought together a small group, including a patient, a health professional, a road engineer, and a designer, to explore options for safer drop-off of patients at the hospital. This group sat around a large (A0) size map of the road layout of the hospital and sketched different solutions on tracing paper, bringing technical expertise and the stories into the conversation as they proposed and negotiated possibilities. A snapshot of this interaction can be seen in Fig. 2.

### 3.2. Enabling meaningful participation

#### 3.2.1. Establishing an appropriate vocabulary

Opening the discussions in the BOSOP project with patient stories and relating these to emotional terms placed on the map emphasised the experiential parts of a visit to hospital rather than the clinical activities. In contrast to specialised process representations such as clinical care pathways, stories and emotional maps prompted health professionals to think beyond their patients' physical condition to their emotional responses as well as to consider their own emotional experiences. In doing so, the project implicitly established patients' and health professionals' personal phenomenological experience as a valid and relevant form of evidence to be considered in the discussion. These experiences could not then be excluded from discussion by rhetorical moves such as a pejorative labelling of those experiences as '(merely) anecdotal', as described in [6].

The stories and the terms appearing in the emotional map helped to build this new vocabulary of patient experience. First recorded in the home, retold to the patient group, and then retold again to the health professional group, the stories were developed, moulded, and synthesised until they became symbols representing particular concepts for the group. For example, the story of one participant who we call Jane, an elderly lady who fell after



being dropped-off at the hospital by her daughter, came to represent the need to address arrival to the hospital. The following quotation is a public participant using Jane's story in one of the last design activities in the project, many months after the story was first told:

There's one of the patient's stories which was about do you remember [Jane]. . . she fell because her daughter dropped her outside of A+E because the car park was full. . . It's not just about car parking. It's about a lack of drop-off.

The stories and the terms in the emotional map provided a starting point for developing a vocabulary that enabled public participants to contribute on their own terms and to index back to the evidence base of their experiences in design discussions.

### 3.3. Giving permission

The representational artefacts in the BOSOP project were permissive. Storytelling, for example, is a language game that the public participants were likely to have played in the past. The resemblance, along with the prompts provided, allowed them to draw upon their knowledge of this genre to quickly learn to express themselves. As one public participant said, "I knew the overall thing but I didn't [know], but I soon found out it was, you know was plenty of general discussions." As a representational artefact, stories could be ready-to-hand to be used in discussions, differing from alternative professionalised representations, which would likely have been present-at-hand and absorbed more of the attention than the discussion.

Material permissive cues were also present in the encounter setting. The stories were first recorded in public participants' homes, a place that is both familiar and one over which the public participant has control. Creating similar cues in a more formal (university) setting required more thought. The emotion map activity did this by inviting people to discuss in small groups who sat around circular tables with a casually dressed facilitator before contributing to the map. Participants could add information to the map by the simple and familiar action of writing a word on a post-it note. The use of tracing paper placed over the roadway map during the discussions about 'A Road' was similarly permissive, as marking the tracing paper did not deface the original map that might be understood as 'belonging' to the professionals.

### 3.4. Choosing the physical properties

The persistence of the emotion map supported the design activities in a number of ways. Both lay participants and health professionals used it while presenting their stories, each person pointing to different parts of the map as shown in Fig. 3. When groups began to prioritise issues, the participants could remind themselves and each other of the important themes. One health professional said in response to a public participant raising an issue, "oh yes, there were lots of them [post-it notes] for that, weren't there." When the language of discussion turned to clinical themes, the facilitators used the map to re-focus the



Fig. 3. A participant using the emotional map to describe a patient story.

conversation on issues of patient experience. Persistence was a quality particularly important in this set of design activities as it supported the maintenance of the newly established vocabulary.

The size of the emotion map and its placement on the wall away from the conversation tables allowed parallel, unfettered access for adding to the map, and when discussing the map. In contrast to conversations and meetings, in which health professionals can dominate the interaction through their command of language, and familiarity with the structure of meeting agendas and reports, the emotion map altered the normal turn-taking rules [38]. It did not oblige others' to wait for a person to finish or demand that each turn respond to what the last person had said. Although mobility stopped some older people from directly placing post-it notes on the map, the majority of people contributed as seen in Fig. 4. In an activity that could have been easily dominated by stronger personalities, the choice of the physical attributes of the emotion map helped to equalise interaction.

### 3.5. Scaffolding participation

Once design activities move beyond understanding the current situation to exploring future design proposals, they will inevitably require a wider, and perhaps less familiar, vocabulary. Well chosen representational artefacts can 'scaffold' participation, in the sense of providing supports



Fig. 4. Participants putting post-it notes on the emotional map.

for interaction and performance as the new language is learned [39]. For example, to determine the problems for patients with the current out-patient service, the stories of the participants needed to be collated and synthesised. Generally, this task takes considerable, often academic, skill. The emotional map, consisting of a timeline with a series of touchpoints, enabled sorting and synthesising of experience to take place without participants needing to learn the terminology of touchpoints and patient experience. As the map enabled a language game that participants could engage with, they picked up these concepts during (rather than in advance of) the interaction.

Likewise, finding a solution to the drop-off and parking issues seemed beyond the capabilities of the group, and gave rise to a sense of disempowerment:

I'm certainly not an expert in road management. So I can only see what's there and perhaps have some thoughts about minor changes. You really need some experts to look at it.

The use of the large map and tracing paper as representational artefacts scaffolded the development of a new language game that allowed the group to work with road engineers and designers to solve the problem together. The participants sketched out ideas, this becoming the language of collaboration. Each participant then applied their expertise to the proposition at hand. The following exchange took place between a public participant and a professional in a discussion about the cross-walk to the hospital entrance:

Professional: Is that this one here?

Public participant: It affects people travelling by bus particularly.

Professional: Yes, you come across here.

Public participant: You've got the slope up from the road

The content of the conversation is not remarkable in itself, but it allows the public participant to recall and communicate relevant and detailed experiential knowledge (in this case the experience of someone arriving by bus and climbing the steps or sloping path to the outpatients' entrance) at the appropriate time when the professional is considering possible redesign options.

#### 4. Discussion

Opportunities for the public to participate in the design of health services at the higher levels of the ladders of participation, commonly include sitting on trust boards, attending research meetings, and inputting into service design sessions. All of these activities place public participants in the middle of existing language games, whether they be clinical, managerial, or research. As considerable professional knowledge and experience is needed to partake in these language games, many public participants are unable to effectively use this opportunity to influence decision-making. We would suggest that the language game problem accounts for at least part of the well-described gap between policy goals to encourage participation and the practical reality of tokenism [5].

Professionalisation of public participants through training [21] is currently necessary to enable public participants to take part in the language games used in health service design decision-making. This case-study illustrates that careful design of representational artefacts provides an alternative mechanism for facilitating language games that are accessible to broader audiences. Work by other participatory designers extends these findings to groups that would likely be marginalised in the participation process, such as those with aphasia [33], amnesia [34], or children with autism [35]. Collaborative engagement in language games such as those used in this project, also has the potential to alter professional and managerial relationships with patients, carers and other representatives, a factor that has been identified as important for achieving organisational change [14].

We would also argue that representational artefacts play an important role as boundary objects between public participants and health professionals. They can become persistent collaborative objects, taking on new meanings when used in different settings. For example, the emotional map was 'plastic' enough to make it easy for the public participants to contribute to and edit. However, it was also sufficiently structured and stable that it could be employed later in discursive decision making, and in communicating with other stakeholders who were not involved in its creation. Considered in this way, using appropriate representational artefacts not only reduces the pressure for professionalisation of public participants, but also reduces pressure for de-professionalisation of health professionals. Instead it provides a mechanism that enables both parties to collaborate drawing on their own familiar language games.

The detail of our study points to four characteristics of the representational artefacts used that engendered participation in this setting:

- They established and maintained an appropriate vocabulary that retains patient priorities rather than organisational ones in discussions.
- They gave permissive cues for patients to participate.
- Their physical properties, in this case persistence and size, actively encouraged equal participation.
- They scaffolded interactions with experts, to enable meaningful participation in complex health service design activities.

While we would not expect the characteristics to stay the same in different settings, they do draw attention to the importance of considering the characteristics of the representational artefact in detail. As Oliver et al. [13] note, existing literature rarely reports in detail the specific methods used in collective decision making in public participation. Those authors that do specify the detail of their decision making methods often do not report on the representational artefacts used in the discourse, focusing primarily on verbal or textual interactions (see for example [40]). We would suggest that the lack of current discourse about the detail of method, and more specifically to the representational artefacts used, misses an opportunity to consider ways to address the current policy–practice gap.

Attention to the characteristics of the representational artefact raises the further question of what kinds of representational artefacts are appropriate to the public voice(s). It has been noted that professionalised public participants often move from a focus on their experiential knowledge to a discourse located within the knowledge paradigm of science [21]. Those organisations that facilitate public involvement might want to consider drawing on the 'collective resource approach,' [41] which proposes that organisations should develop their own understandings and languages for discussing new propositions, to ensure that issues and values that are important to them are not implicitly expunged from debates. Such an approach would speak to the call for such mediating organisations to continue to develop their methods [42].

In this paper, we have highlighted the important, but often unrecognised, role that the careful construction of representational artefacts for discussing current and future design proposals plays in enabling meaningful participation. In doing so, we do not want to suggest that choosing suitable representational artefacts is *sufficient* to ensure meaningful participation. It remains the case that attention must be paid to the specific and ever changing political landscape in which participation is embedded [12], the broad mosaic of relationships through which participation in decision making takes place [12,17] and that specific strategies are required to address these factors, e.g. the inclusion strategies proposed by [40].

The creation or choice of appropriate representational artefacts to meet the goals of a particular design activity or encounter is one of the central methodological concerns of the field of design, particularly participatory design. A participatory designer could, for example, work with public participants and/or health professionals to develop representational artefacts that support a vocabulary that reflected both groups' priorities. We suggest that including participatory designers in projects could support more meaningful public participation in health service design and improvement and address important aspects of this policy–practice gap.

### Source of funding

This article presents independent research commissioned by the National Institute for Health Research (NIHR) under the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) programme for Cambridge and Peterborough and South Yorkshire. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

### Conflict of interest

None.

### Acknowledgements

Better Outpatient Services for Older People (BOSOP) was funded by NHS Sheffield. We acknowledge the valuable contributions of all the staff, patients, carers

and advocates who participated in BOSOP as well as the support of Sheffield Churches Council for Community Care (SCCCC) in the BOSOP project. We would also like to acknowledge Jill Thompson's insights on earlier drafts.

### References

- [1] Boote J, Telford R, Cooper C. Consumer involvement in health research: a review and research agenda. *Health Policy* (Amsterdam, Netherlands) 2002;61:213–36.
- [2] Department of Health. Creating a patient-led NHS; 2005.
- [3] UK Parliament National Health Service Act 2006. London: HSMO; 2006, p. c41.
- [4] Löfgren H, Leeuw Ede, Leahy M. Democratizing health consumer groups in the policy process. *Edward Elgar Publishing*; 2011, p. 272.
- [5] Ward PR, Thompson J, Barber R, Armitage CJ, Boote JD, Cooper CL, Jones GL. Critical perspectives on consumer involvement in health research: epistemological dissonance and the know-do gap. *Journal of Sociology* 2009;46:63–82.
- [6] Rose D, Fleischmann P, Tonkiss F, Campbell P, Wykes T. User and carer involvement in change management in a mental health context: review of the literature. In: Report to the National Co-ordinating Centre for NHS Service Delivery and Organization R&D. London: Service User Research Enterprise, Institute of Psychiatry, De Crespigny Park; 2002.
- [7] Dyer S. Rationalising public participation in the health service: the case of research ethics committees. *Health & Place* 2004;10:339–48.
- [8] Carrick R, Mitchell A, Lloyd K. User involvement in research: power and compromise. *Journal of Community & Applied Social Psychology* 2001;11:217–25.
- [9] Beresford P. User involvement in research: exploring the challenges. *Journal of Research in Nursing* 2003;8:36–46.
- [10] Barnes M. Power, participation, and political renewal: theoretical perspectives on public participation under new labour in Britain. *Social Politics: International Studies in Gender, State & Society* 2004;11:267–79.
- [11] Investing in Engagement. <http://www.investinengagement.info/SiteGuidetop>
- [12] Gibson A, Britten N, Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health* (London, England: 1997) 2012;16:531–47.
- [13] Oliver SR, Rees RW, Clarke-Jones L, Milne R, Oakley AR, Gabbay J, Stein K, Buchanan P, Gyte G. A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations* 2008;11:72–84.
- [14] Fudge N, Wolfe CDA, McKeivitt C. Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal* 2008;336:313–7.
- [15] Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P. Systematic review of involving patients in the planning and development of health care. *British Medical Journal* 2002;325:1263.
- [16] Arnstein S. A ladder of citizen participation. *Journal of the American Planning Association* 1969;35:216–24.
- [17] Titterton JQ, McCallum A. The snakes and ladders of user involvement: moving beyond Arnstein. *Health Policy* 2006;76:156–68.
- [18] Attree P, Morris S, Payne S, Vaughan S, Hinder S. Exploring the influence of service user involvement on health and social care services for cancer. *Health Expectations* 2011;14:48–58.
- [19] Richardson A, Sitzia J, Cotterell P. Working the system. Achieving change through partnership working: an evaluation of cancer partnership groups. *Health Expectations* 2005;8:210–20.
- [20] Santry C. FT staff governors lack skills to take on boards. *Health Service Journal*; 2009, p. 11.
- [21] Thompson J, Bissell P, Cooper C, Armitage CJ, Barber R. Credibility and the professionalized lay expert: reflections on the dilemmas and opportunities of public involvement in health research. *Health* (London, England: 1997) 2012.
- [22] Lockett R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. Training for service user involvement in health and social care research: a study of training provision and participants' experiences. *Worthing: Worthing and Southlands Hospitals NHS Trust/Worthing*; 2004 (The TRUE Project).
- [23] Greenbaum JM, Kyng M. Design at work: cooperative design of computer systems; 1991.
- [25] Ehn P, Kyng M. Cardboard computers: mocking-it-up or hands-on the future; 1992, p. 169–96.
- [26] Wittgenstein L. Philosophical investigations. *John Wiley & Sons*; 1953, p. 592.



- [27] Bråten S. Model monopoly and communications systems theoretical notes on democratization. *Acta Sociologica: Journal of the Scandinavian Sociological Association* 1973;16:98–107.
- [28] Ehn P. In: Schuler D, Namioka K, editors. *Scandinavian design: on participation and skill in participatory design: principles and practices*. Hillsdale, NJ: Laurence Erlbaum Associates; 1993. p. 41–78.
- [29] Roth W-M, McGinn MK, Woszczyna C, Boutonné S. Differential participation during science conversations: the interaction of focal artifacts, social configurations, and physical arrangements; 2007.
- [30] Broberg O, Andersen V, Seim R. Participatory ergonomics in design processes: the role of boundary objects. *Applied Ergonomics* 2011;42:464–72.
- [31] Star SL, Griesemer JR. Institutional ecology, 'translations' and boundary objects: amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907–39. *Social Studies of Science* 1989;19:387–420.
- [32] Fischer G. Social creativity: turning barriers into opportunities for collaborative design. In: *Proceedings of the eighth conference on participatory design. Artful Integration: interweaving media, materials and practices – PDC 04*. 2004. p. 152–61.
- [33] Moffatt K, McGrenere J, Purves B, Klawe M. The participatory design of a sound and image enhanced daily planner for people with aphasia. New York, NY, USA: ACM Press; 2004. p. 407–14.
- [34] Wu M, Richards B, Baecker R. Participatory design with individuals who have amnesia. In: *Proceedings of the eighth conference on participatory design. Artful integration: interweaving media, materials and practices – PDC 04*, vol. 1. New York, NY, USA: ACM Press; 2004. p. 214.
- [35] Hayes GR, Hirano S, Marcu G, Monibi M, Nguyen DH, Yeganyan M. Interactive visual supports for children with autism. *Personal and Ubiquitous Computing* 2010;14:663–80.
- [36] Wolstenholme D, Cobb M, Bowen S, Wright P, Dearden A. Design led service improvement for older people. *Australasian Medical Journal* 2010;3:465–70.
- [37] NHS Institute for Innovation and Improvement. *The EBD approach: guide and tools*. Coventry; 2009.
- [38] Sacks H, Schegloff E, Jefferson G. A simplest systematics for the organization of turn-taking for conversation. *Language* 1974;50:696–735.
- [39] Berk L, Winsler A. Scaffolding children's learning: Vygotsky and early childhood education. In: *NAEYC research into practice series*; 1995. p. 7.
- [40] Elberse JE, Caron-Flinterman JF, Broerse JEW. Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives. *Health Expectations* 2011;14:225–39.
- [41] Floyd C, Mehl W-M, Resin F-M, Schmidt G, Wolf G. Out of Scandinavia: alternative approaches to software design and system development. *Human–Computer Interaction* 1989;4:253–350.
- [42] Tenbelsel T. Interpreting public input into priority-setting: the role of mediating institutions. *Health Policy* 2002;62:173–94.